

Special Medical Services

Planned Activities

State Fiscal Year 2007

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Introduction and Background

Special Medical Services (SMS) is the State Title V Program for Children with Special Health Care Needs (CSHCN), a population estimated to exceed 47,000 New Hampshire children. The SMS programs are funded by general funds and the Maternal and Child Health Bureau (MCHB) Title V Block Grant to the States. SMS provides direct services to eligible children, enabling services, population-based services, and infrastructure-building services, to the CSHCN population and their families. The public health services of SMS are illustrated in Figure 1, which also illustrates the MCHB pyramid model. See Appendix 1 for a description of the four core elements. The NH-SMS service system construct is described in Appendix 2.

New Hampshire ranks the ninth highest in the nation for the prevalence of children age 0-17 with special health care needs. The NH prevalence is 15.2 % and the national average is 12.8%². Children with special health care needs are defined as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.³ Senate Bill 472 was enacted in 2004, in which New Hampshire State statutes were revised, replacing the term "crippled children" with the term "children with special health care needs" (RSA 132:1, 132:11, and 132:13), consistent with the operational definition accepted by the States and US territories.

SMS is required to provide specified data about the National and State Performance Measures and certain Health Systems Capacity Indicators defined in the block grant. Progress on the measures is indicated by "core outcomes", defined by the Centers for Disease Control and Prevention, National Center for Health Statistics, per the national and state-level data⁴ obtained by the National Survey of Children with Special Health Care Needs, 2001⁵. Twenty-eight items in the data are organized to comprise five Core Outcomes. See the SMS SFY04 Report of Planned Activities for tables of the national averages and the New Hampshire ratings for the Core Outcomes. The National Survey has been repeated in 2005-2006 and data should be available in 2007.

The Special Medical Services Section's (SMS) activities for State Fiscal Year 2007 address selected stakeholder-identified needs and priorities emerging from the results of a comprehensive five-year needs assessment process and organizational capacity assessment done in FY '05.

¹ Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001. Version: Revised sampling weights, version 2. Analysis Date: April 28, 2003.

² Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001. Version: Revised sampling weights, version 2. Analysis Date: April 28, 2003 and Data Resource Center on Children and Youth with Special Health Care Needs (interactive database for the State-level data from the National Survey).

³ McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

⁴ Data source: same as reference #1, noted hereafter as "The National Survey".

⁵ van Dyke PC, McPherson M, Strickland BB, Nesseler K, Blumberg SJ, Cyamon ML, Newacheck PW. The National Survey of Children with Special Health Care Needs. Ambulatory Pediatrics 2:29-37. 2002.

Figure 1

The SMS Service Structure as Related to the MCHB Pyramid

Child Development Program, Neuromotor Program, and Nutrition, Feeding and Swallowing Program

Information and Referral, Family Advocacy and Support, and Community-Based Care Coordination

Medical Home System for CSHCN, Screening and Follow-Up, Public Education, and Integration of Mental Health Services

Statewide Needs Assessment, Leadership
for Policy and Standards Development, Evaluation
of Services, Quality Assurance and Quality Improvement,
Planning and Coordination, Community Partnerships, Monitoring
and Reporting, Training, Work Force Development, Service Systems
Development, Legal Requirements, and Information Systems Development.

Planning Process for State Fiscal Year 2006

The planning for FY07 was again informed by the results of the New Hampshire Five Year Needs Assessment, and in particular the results of the Delphi process reported in the 2004 Executive Summary "Assessing Needs and Resources for Children with Special Health Care Needs in New Hampshire". Other data informing the planning process and identification of emergent priorities include the 2004 New Hampshire Survey of Children with Special Health Care Needs Receiving Supplemental Security Income for Their Own Disability, the 2004 Information and Referral Report, and the results of selected New Hampshire data analysis reported in the SMS-authored article recently published in the Maternal and Child Health Journal, "Economic Impact on Families Caring for Children with Special Health Care Needs in New Hampshire: The Effect of Socioeconomic and Health-Related Factors"

Special Medical Services staff analyzed stakeholder input from a wide variety of external sources and integrated those results with the results of a facilitated internal process, the Capacity Assessment for State Title V (CAST-5).⁷ The CAST-5 assessment and planning tools are designed to assist the state Title V programs in examining their organizational capacity to carry out core MCHB public health functions. These functions are closely tied to the Title V National Performance Measures. The CAST-V process in New Hampshire was initiated by the Maternal Child Health Section and jointly conducted with SMS staff and was completed in 2005.

National Performance Measures for CSHCN: Plans for SFY07

National Performance Measure 02: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

According to the NH data from the National Survey of CSHCN, accessed from the Data Resource Center for CSHCN:

- > 55% of families surveyed felt like a partner in decision-making and were satisfied with the services received (Outcome #1).
- ➤ Of those with insurance coverage, 45% did not meet the criteria for success for this outcome.
- ➤ Of those without coverage, 55% did not meet the criteria.
- ➤ Of the respondents reporting specific types of special health needs, 58% of those whose children had functional limitations did not meet the criteria.

⁶ Bumbalo, Judith; Ustinich, Lee; Ramcharran, Darmendra; Schwalberg, Renee, Maternal and Child Health Journal, Volume 9, Supplement 1, June 2005, pp. S3-S11(1)

⁷ CAST-5 is an initiative of the Association of Maternal and Child Health Programs and the Johns Hopkins University Women's and Children's Health Policy Center (WCHPC), in partnership with the Health Resources and Services Administration Maternal and Child Health Bureau.

➤ Thirty-eight percent of those managed by prescribed medications, 48% of those needing above routine services, and 42% of those reporting use of Rx meds combined with heightened service use, did not meet the success criteria for this outcome.

These figures indicate that clinical services for NH CSHCN not under direct influence of the State Title V program (SMS) may need technical assistance and/or consultation to improve parent satisfaction

- ❖ SMS will continue to support NH Family Voices with a contract for \$137,348 and Upper Valley Parent to Parent Support with a contract for \$16,662.
- All SMS supported programs (contract and state supported) are now required to conduct and submit parent satisfaction surveys focusing on quality of care indicators. Based on the results of these surveys, each program will be asked to submit a plan for increasing satisfaction with services received.
- SMS will focus on providing support to medical home sites in their endeavors to increase parent participation and family-centered care. SMS is working with practice teams in Hillsborough and Dover on completing brochures and wall posters that detail what patients and families can expect from medical home staff. Parent partners are active participants in these initiatives and are clearly identified on all materials.
- Through activities associated with NPM#6 and the *Integrated Care for NH CSHCN grant*⁸, particular efforts will be made to recognize youth as experts in their own care by expanding on development of the Health Care Transition Coalition. Plans are to increase the number of participating families and to establish a separate youth initiative. It is expected that these activities will have a direct influence on increasing family participation in decision-making.
- ❖ SMS activities in the next fiscal year will focus on recruiting families from diverse cultures to participate in the decision making process that impacts the system of care for CSHCN.
- ❖ A major goal of the Integrated Care for NH CSHCN grant is to develop a collaborative infrastructure to support and sustain a culturally competent system of providing care coordination within medical homes.
- ❖ During '06 -- '07 the services of the National Center for Cultural Competency will be brought to New Hampshire to begin raising levels of awareness and to provide needed training to personnel and providers.
- ❖ Efforts will also focus on establishing an ongoing collaborative relationship with the Minority Health Coalition in Manchester to plan and implement a series of outreach

⁸ A MCHB funded initiative through the Hood Center at Dartmouth Hitchcock Medical Center; SMS is a major collaborator in this project.

activities within minority communities in order to increase knowledge of family needs and to increase participation in the system of care.

National Performance Measure 03: The percent of CSHCN age 0 to 18 who receive coordinated, ongoing comprehensive care within a medical home.

According to the NH data from the National Survey of CSHCN, accessed from the Data Resource Center for CSHCN:

- > 55% of families surveyed reported receiving coordinated, ongoing, comprehensive care within a medical home (Outcome #2).
- ➤ Of those with insurance coverage, 44% did not meet the criteria for success for this outcome.
- ➤ Of those without coverage, 54% did not meet the criteria.
- ➤ Of those reporting specific types of special health needs, 57% with children with functional limitations did not meet the criteria.

These figures indicate that clinical services for NH CSHCN not under direct influence of the State Title V program (SMS) may need technical assistance and/or consultation to develop and improve the medical home system in New Hampshire

- ❖ SMS will continue to develop the staff position (public health nurse coordinator) affiliated with the Medical Home Initiative. The coordinator (Hoerbinger) is the SMS liaison to the Center for Medical Home Improvement (CMHI) staff
- ❖ The contract for "The Medical Home Project for Children with Special Health Care Needs" has been awarded to commence October 2007. The focus for this SMS contract will include the following activities: focus on statewide Medical Home planning; develop a Medical Home network and registry; create policy regarding Medical Home development; and provide technical assistance to medical practices working to develop medical homes.
- The Medical Home liaison will facilitate Medical Home Practice meetings for pediatric and family medicine teams, and attend Medical Home Learning Collaborative meetings to represent SMS and to assist in facilitating the sessions.
- ❖ In addition, she will continue to define and refine the resource role for practice based care coordinators, providing case consultation and modeling care coordination activities for complex children and families.
- ❖ SMS Coordinator Staff will collaborate with staff from the Center for Medical Home Improvement to formalize "spread" of Medical Home Model throughout NH. This will include but not be limited to meeting formally six (6) times annually, communicating via telephone or e-mail on an as needed basis, working together on Medical Home related documents, forms, and presentations.

National Performance Measure 04: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

NH data from the National Survey of CSHCN reports adequacy of insurance for 62% of families surveyed. The Date Resource Center for CSHCN indicates that:

- ➤ 94% of NH CSHCN were insured; however, 38% of families did not meet all of the criteria for success for Outcome #3, adequacy of insurance
- > 58% of families below 100% of the FPL did not meet the success threshold for this outcome.
- ➤ Of those reporting specific types of special health needs, 57% with children with functional limitations, 24% of those managed by prescription medications, 49% of those with an above routine need/use of services, and 36% of those with Rx meds and higher service use, combined, did not meet the success criteria for this outcome.

These figures indicate that assessment of the parents' perceptions of inadequacy of insurance for their children with special health care needs warrants further attention for strategic planning purposes.

The SMS follow-up of CSHCN/SSI applicants will continue for CSHCN who are not clients of SMS and who are not receiving Medicaid. The family is sent the appropriate information, enrolled, referred, or discharged as indicated, and provided further follow-up if needed.

- ❖ It is unknown how the essential duties of the Health Care Financing Specialist (vacated in early March, 2006) position might be re-assigned until the vacancy is filled. This position has been tasked with many responsibilities related to the implementation of the Special Medical Services Annual Plan, which includes all performance measures and planned activities set forth in the block grant application. Therefore, planned activities are difficult to articulate with certainty, at this time.
- ❖ SMS staff will analyze the data from the completed Survey of Families of Children receiving SSI, 2006, to determine the nature and extent of the need for care coordination to help fill identified and prioritized gaps associated with the limitations of Medicaid for this group of children.
- ❖ The results of the follow-up survey will inform future planning and allocation of resources. The majority of the population surveyed receives both SSI and Medicaid. Part of the assessment is to determine what needs have been requested to be met, and what needs have subsequently been met, or could be met, within the Medicaid program.
- ❖ The insurance needs of 18-21 year old YSHCN in New Hampshire have become increasingly evident in the past year. Successful health care transition for this population requires the availability of primary providers/specialists with an understanding of the needs of these youth, as well as a means to pay for this care.

❖ SMS staff (Collins) will seek consultation from the Catalyst Center and undertake a policy analysis in order to make recommendations to DHHS regarding this issue. The project will be done in collaboration with the NH Council of Children and Adolescents with Chronic Health Conditions whose mandate is to advise DHHS regarding policy/program development and to increase awareness of the unique needs of CSHCN and their families.

National Performance Measure 05: The percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

According to the Data Resource Center for CSHCN, the National Survey of CSHCN results for NH (Outcome #5):

- > 78% of NH respondents thought the community-based service systems were organized so families could use them easily.
- Among the respondents reporting an above routine need/use of services, and among those whose children experienced functional limitations, 30% of both groups did not think the services were organized for ease of use.
- ➤ Of those with insurance coverage, and of those with no current insurance, 22% of both groups did not think the services were organized for ease of use.

These figures indicate that community-based services for NH CSHCN not under direct influence of the State Title V program (SMS) may need technical assistance and/or consultation to improve parent satisfaction among the population experiencing more complex and severe conditions.

- ❖ The Nutrition Network and the Feeding and Swallowing Program will continue to explore cost sharing possibilities and strategies to maximize third party reimbursement. Special focus will be on strategies for reimbursement related to diabetic education for children and families.
- ❖ Per the performance measures in the SMS contracts for Nutrition, Feeding and Swallowing services, a pilot program for an interdisciplinary feeding assessment/intervention team will be established at Child Health Services. These initiatives will expand community-based services for a targeted group of children and families.
- ❖ A major focus of activity will be in relation to the MCHB funded grant entitled Integrated Care for NH CSHCN. SMS is a collaborator with the Hood Center at DHMC for this initiative. The goals of this project are to:
 - develop a three level consultative model of comprehensive care coordination that supports practices' development of care coordination within the context of a medical home;
 - build capacity to meet the transition needs for YSHCN and develop collaborative infrastructure within NH to support;

- and sustain a culturally competent integrated system of providing care coordination within medical homes.
- ❖ Outreach to families of children receiving SSI will continue. The specifics of the plan will depend on the results of a follow-up survey (based on the 5 year needs assessment) recently completed by this population.
- ❖ SMS will support the efforts of a contractor (Child Health Services) to collaborate with the Manchester Community Mental Health Center in a project to co-locate a mental health professional in a primary care and child development setting in order to integrate services. In addition, SMS will support care coordination and mental health assessments for clients in the Manchester Teen Clinic who have dual (special needs/mental health) diagnoses.

National Performance Measure 06: The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.

According to the Data Resource Center for CSHCN, the National Survey of CSHCN results for NH (Outcome #5):

- Nationally, only 5.8% of youth age 13 to 17 is receiving all or most of the services necessary to make transitions to adult life, adult health care, work, and independence.
- ➤ The survey results for New Hampshire provisionally indicate that only 3.3% of YSHCN are attaining this Core Outcome. New Hampshire results of the five elements are as follows (see footnote 10):
 - 51.7% of doctors had spoken with the family about their child's changing needs as they become adults; 66.5% of the families indicated that their youth did have a plan for addressing changing needs; 41.1% reported that doctors had discussed the shift from a pediatric to an adult medical provider; 2.7% of families indicated that their child had received guidance and support in the transition to adulthood; 16.7% of those surveyed had received vocational or career training
- ❖ The Youth Health Care Transition Project (partial support from the Champions for Progress Award), ended in June 2006. We will continue offering direct consultation to the project pediatric practices to directly assist them in the transition of YSHCN. We will make project materials available and offer direct consultation to other primary care practices. We will provide consultation as requested to SMS care coordinators on the transition of individual youth. The Transition Work Group will continue to meet bimonthly to discuss health care transition issues and cases.

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⁹Due to small sample size for this survey item, this estimate does not meet the National Center for Health Statistics standard for reliability or precision. This occurred because the item was introduced late into the 2001 survey cycle and will be corrected when the survey is repeated in 2005.

- ❖ The Health Care Transition Coalition will be expanded to include additional interested professionals such as middle and high school nurses and specialty care providers. Parent participation has been excellent. Our planned focus is to formalize a statewide plan to address family and professional education about health care transition.
- ❖ We will participate in ongoing statewide collaborative education efforts such as the Dreams into Action conference. We will join an existing interagency work group on transition (the National Community of Practice in Support of Transition) to promote inclusion of health care issues and health care transition in the developing system. We will work closely with the new MCHB/HRSA Integrated Services for NH CSHCN Grant staff to expand health care transition activities in additional primary care practices.
- ❖ An ad hoc work group of private and public stakeholders concerned about the transition needs of individuals over the age of 16 with complex medical and developmental needs will continue to explore capacity issues related to caring for these young adults.

New State Performance Measures

State Performance Measures that emerged from the NH Five Year Needs Assessment and the identification of statewide priorities have been addressed by SMS. Two of these measures (reducing obesity in NH children and respite care workforce development) are explicit to New Hampshire CSHCN, the population served by Special Medical Services.

SPM #9 Obesity: [REVISED]: The percent of CSHCN who are at risk for/are overweight or obese

GOAL: To increase the number of CSHCN, with impaired mobility, who receive individualized education regarding proper nutrition and safe physical activity.

DEFINITION: The percent of CSHCN who are at a risk for/are overweight or obese (as determined by diagnosis and/or BMI criteria as established by the CDC).

HEALTHY PEOPLE 2010 OBJECTIVE: 19-3 Reduce the proportion of children and adolescents who are overweight or obese.

DATA SOURCE: Diagnoses from caseload lists, SMS database information, Nutrition, Feeding & Swallowing service notes.

SIGNIFICANCE: The percentage of children and adolescents in the state who are obese or overweight is higher than the national average and appears to be increasing; however, there is no substantive information regarding the CSHCN population. The most common source of data is the NHANES survey. According to the NHANES 1999-2002 the population of children with "limitations" who are at-risk-for overweight is 50.9% and who are overweight is 29.7%. However this study excluded children who were unable to weight bear and stand. Therefore, the indication is that CSHCN have significant numbers related

to overweight and obesity issues but the population with impaired mobility is not clearly represented. This is important because the impact of overweight and obesity on the functional status of CSHCN who have mobility impairment is critical to their development of skills for independent living.

- ❖ Design and develop pilot program that will provide education and support for healthy eating and safe physical activity for children with mobility impairment, who are at risk for/are overweight/obese.
- ❖ Implementation of this pilot program titled: "Youths with Special Needs: Food and Fitness Program". This project will include: a) identifying with more detail the roles and requirements of the clinical providers; and b) identifying the funding sources.
- ❖ Implement data collection and review process jointly between SMS and Implement data collection (BMI, ht. & wt.) and review process jointly between SMS and DHMC in reference to the CSHCN populations served with neuromotor conditions and Spina Bifida.
- ❖ A SMS Care Coordinator (Butler) will be on the Steering Committee of the NH Healthy Schools Coalition, which is the NH affiliate for the National Action for Healthy kids (AFHK).

SPM #10 Respite and Child Care for Families of CSHCN: [REVISED]: The percent of respite/childcare providers, serving medically and behaviorally complex children, who have participated in competence-based training.

GOAL: To develop/implement a respite care training curriculum and competencies that identify core information basic to the broad needs of medically and behaviorally complex children

DEFINITION: The percent of respite/childcare providers, serving medically and behaviorally complex children, who have participated in competence-based training.

HEALTHY PEOPLE 2010 OBJECTIVE: N/A

DATA SOURCE: State Title V program checklists, surveys of stakeholder programs, program registration/attendance records.

SIGNIFICANCE: There is an identified lack of respite and child care available, by a trained work force, for medically and behaviorally complex children with special health care needs. The National Survey of CSHCN results for NH indicate that 37% (n=1,936) of the children that needed respite services did not receive such services. The group reporting the need for respite constituted approximately 8% of New Hampshire CSHCN.

❖ Complete and submit, by September 30, 2006, an application to the New Hampshire Endowment for Health for a three-year planning grant. The intent is to identify the core

competencies necessary to provide quality respite/childcare services to CSHCN; to identify the training mechanisms that will meet the wide diversity of provider workforce needs; and to initiate curriculum development that will be shared with identified partners across the State of NH.

❖ If funding is obtained, the formal project will commence in January of 2007. Planning will also involve an investigation of mechanisms to maintain sustainability and to tie funding for respite services to quality training initiatives.

Appendix 1

The Maternal Child Health Bureau Pyramid of Services¹⁰

Direct Health Services - Those services generally delivered one-on-one between a health professional and a patient in an office, clinic, or emergency room...services include what most consider ordinary medical care.... State Title V programs support ... services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and subspecialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Enabling Services - Services that allow or provide for access to and the derivation of benefits from the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC, and education. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, **care coordination**¹¹, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition, and social work.

Population-Based Services - Preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition, and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system...and whether insured or not.

Infrastructure Building Services -The services that are the base of the MCH pyramid of health services and form its foundation are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems, including development and maintenance of health services standards/guidelines, training, data, and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based, and culturally competent.

¹⁰ https://performance.hrsa.gov/mchb/mchreports/Glossary.html (accessed 7/29/05)

¹¹ Care Coordination Services for CSHCN - Those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. [Title V Sec. 501(b)(3)]

Appendix 2

Constructs of the New Hampshire CSHCN¹² Service System¹³

The State service system is congruent with the Goals and Objectives of the Special Medical Services Section (formally the Bureau of Special Medical Services), 1998, and is developed within a framework of contemporary applied research (evidence-based best practices).

1. SMS Program Collaboration with Other State Agencies and Private Organizations

SMS staff establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of services for CSHCN. SMS staff collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

2. SMS Support for Communities

The SMS staff emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and modest financial or in-kind resources for partners engaged in systems development to assure that the unique needs of New Hampshire CSHCN are met.

3. Coordination of Health Components of Community-Based Systems

A mechanism exists in communities across the State for coordination of health services with one another. This includes coordination among providers of primary care, habilitative and rehabilitative services, other specialty medical treatment services, mental health services, and home health care.

4. Coordination of Health Services with Other Services at the Community Level

A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

¹² **Children with Special Health Care Needs (CSHCN) - (***For budgetary purposes*) Infants or children from birth through the 21st year with special health care needs whom the State has elected to provide with services funded through Title V. CSHCN are children who have health problems requiring more than routine and basic care, including children with or at risk of disabilities, chronic illnesses and conditions and health-related education and behavioral problems. https://performance.hrsa.gov/mchb/mchreports/Glossary.html (accessed 7/29/05) and adapted for Special Medical

¹³ https://performance.hrsa.gov/mchb/mchreports/Glossary.html (accessed 7/29/05 and adapted for Special Medical Services.)